



Comparative Effectiveness Research Review Disposition of Comments Report

Research Review Title: *Interventions for Feeding and Nutrition in Cerebral Palsy*

Draft review available for public comment from August 6, 2012 to September 3, 2012.

Research Review Citation: Ferluga ED, Archer KR, Sathe NA, Krishnaswami S, Klint A, Lindegren ML, McPheeters ML. Interventions for Feeding and Nutrition in Cerebral Palsy. Comparative Effectiveness Review No. 94. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2007-10065-I) AHRQ Publication No. 13-EHC015-EF. Rockville, MD: Agency for Healthcare Research and Quality. March 2013. Available at: www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Comments to Research Review

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The tables below include the responses by the authors of the review to each comment that was submitted for this draft review. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

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| Commentator & Affiliation | Section | Comment | Response |
|---------------------------|-------------------|---|--|
| Peer reviewer #1 | General | Yes, it is all very detailed and explained very well. | Thank you for your comments. |
| Peer reviewer #1 | Introduction | Good introduction. Very detailed. | Thank you for your comments. |
| Peer reviewer #1 | Methods | Yes to all questions. | Thank you for your comments. |
| Peer reviewer #1 | Results | Yes to all questions. Very thorough. | Thank you for your comments. |
| Peer reviewer #1 | Discussion | Yes. I did not realize how little evidence based literature there was on feeding in children with CP. I know that information on adults in CP is limited. | Thank you for your comments. We hope that the report will spur more research in this area. |
| Peer reviewer #1 | Clarity/Usability | Yes to all questions. | Thank you for your comments. |
| TEP Member #1 | Executive Summary | On p. ES-17 (lines 21-22), in the sentence below, consider inserting "there is" prior to "a clear need for rigorous" to aid the reader's understanding. The sentence is fine in a later section on Conclusions. "Evidence for behavioral interventions for feeding disorders in cerebral palsy is weak, with some studies suggesting that sensorimotor interventions and positioning may be beneficial, but a clear need for rigorous," | We have edited the text as noted. |
| TEP Member #1 | Introduction | Good overall introduction. | Thank you for your comments. |
| TEP Member #1 | Methods | Some may not like the Behavioral Interventions title because it covers everything else. But even if you parse out the therapeutic devices/equipment, feeding interventions (like positioning, oral-otor interventions, etc.), I don't think it will change the outcome because of the lack of studies on these areas. | We agree that there are multiple ways to categorize these interventions. We selected the overarching behavioral categorization in consultation with our Technical Expert Panel and recognize that it is not without limitations; however, as you note, categorizing the studies using other schema would not change our conclusions. |
| TEP Member #1 | Methods | The methods were clearly described and charts were helpful. | Thank you for your comments. |
| TEP Member #1 | Results | Yes, it's appropriate and well-described. Tables and appendices are informative. | Thank you for your comments. |





| Commentator & Affiliation | Section | Comment | Response |
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| TEP Member #1 | Results | There is one recent article that may pertain although I am not sure if it meets all the inclusion criteria. Sample - all kids with CP. One of their outcome measures: Pediatric Motor Activity Log (PMAL) includes items like holding a cup, eating finger foods, and other ADLs. See below. Multicenter randomized controlled trial of pediatric constraint-induced movement therapy: 6-Month follow-up Case-Smith, J 2012 Jan-Feb The American Journal of Occupational Therapy | Thank you for pointing out this study. We reviwed this citation and another related study (PMID 22699104). Neither study met our inclusion criteria because they did not specifically address feeding outcomes separately from the overall composite outcome measure (PMAL). |
| TEP Member #1 | Discussion/Conclusions | Yes - difficult because of the paucity of studies but well done. | Thank you for your comments. |
| TEP Member #1 | Clarity/Usability | Yes. I liked how the conclusions were written for different stakeholders. | Thank you for your comments. |
| TEP Member #2 | Executive Summary ES-3 | perhaps consider adding behavioral etiologies as a large part of the review deals with Behavioral Therapies. Habitual aversive responses are likely to be more amenable to such therapy than oro-motor deficit caused by neurological impairment. | We agree and have added the phrase "behavioral etiologies" to this sentence. |
| TEP Member #2 | Executive Summary ES-3 | This is a fine point clinically. Some advocate tube feeding for ANY aspiration but most experts recognise that action is required for CLINICALLY-SIGNIFICANT aspiration. | No revision needed. |





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| TEP Member #2 | Executive Summary ES-12 | The issue is not only to identify harms of clinical importance but also harms that can be avoided by more elegant management strategies whilst at the same time preserving the positive effects of the intervention. An example of this is the risk of overfeeding following G tube insertion. This is the import of the study you have excluded by Vernon-Roberts et al 2010). This study showed that by feeding a Low-Energy formula instead of standard enteral formula it was possible to achieve weight gain in previously malnourished CP children WITHOUT excessive weight gain. | This study focuses on a specific type of feed, rather than on the effectiveness of the gastrostomy itself. Nonetheless, it does provide pre and post data on weight and other measures of interest for children with CP. Therefore, we have added it in the section on harms as a study intending to assess means of preventing overfeeding. |
| | | This study was excluded (X-4) because it was alleged not to "address interventions of interest". I disagree; this is an important study because it is very unlikely to be repeated It used the state of the art methodology for assessing body composition (Doubly-labelled water) and was a before-and-after design. The study used very strict inclusion criteria so that a homogenous study population of the most severely affected (GMFCS IV/V) children with CP was studied.112 children with CP were referred during the study period but only 14 satisfied the inclusion criteria. As a result the study took 4 years rather than 2 to complete. This study illustrates some of the significant problems in undertaking studies in children with CP which I will return to below. | |
| TEP Member #2 | Executive Summary ES-17 | Caution is needed with this interpretation as what constitutes "underweight" for a child with CP is not the same as for a neurologically normal children. The papers which reported that some children remained underweight were using inappropriate reference standards designed for normal children. An improvement from a weight-for age Z score of -3.0 to -1.5 probably reflects a return to 'normality for a CP child whilst a normal child would still be considered to be underweight. | We have added a comment in the discussion and in the conclusion suggesting that caution should be used in interpreting statements of underweight for these reasons. |
| TEP Member | Executive Summary | Mention should also be made of the risk of overfeeding | We have added overfeeding as a potential harm in this |
| #2 | ES-17 | that can ensue from gastrostomy tube feeding. | statement (Conclusions). |
| TEP Member | Results | The References are all out of synch here (assuming that | We have corrected the error in the references. |
| #2 | Pg. 27 | the text numerals refer to those references listed on page 81/166 to 86/166. | |





| Commentator | Section | Comment | Response |
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| & Affiliation TEP Member | Results | so 90 is probably 89 and 91 is probably 90 etc etc. This | We have corrected the error in the references. |
| #2 TEP Member #2 | Pg. 27 Results Pg. 29 | needs careful scrutiny as it is currently very confusing. Not Shapiro but Rempel | We have corrected the error in the references. |
| TEP Member #2 | Results Pg. 29 | This is a further example of the danger in misinterpreting data derived from reference standards designed for normal children but this could be referred to Dr Remple who is on the TEP. Back in 1988 when this study was published the issue of the reference standards was perhaps not appreciated as much as it is now. | As noted above, we have added text about the importance of using appropriate reference standards, and that caution should be used in interepreting those currently in use as applied to studies of this population. |
| TEP Member #2 | Results Pg. 29-35 | check refs | We have corrected the error in the references. |
| TEP Member #2 | Discussion Pg. 41 | or | Corrected |
| TEP Member #2 | Discussion Pg. 46 | This is true and it may be that research utilizing national CP feeding registries will do this. However, it should be acknowledged that children with CP represent a particularly difficult group to research. Their heavily burdened families may not want to engage in research and the difficulties in recruitment to and retention in clinical studies of this group of children must not be underestimated. To some extent this accounts for the relatively poor quality of the evidence base | This is an astute observation and we have added a sentence to this effect in the discussion section. |
| TEP Member #2 | Discussion Pg. 47 | check refs | We have corrected the error in the references. |
| TEP Member #2 | Discussion Pg. 48 | see above cautionary note about determining was constitutes 'underweight' in children with CP | We have noted that those studies that do provide data on weight gain do so against reference populations of typically developing children. These are likely not appropriate reference standards; improvement in z-scores among children with CP may very well be clinically meaningful even if these children do not approach weight standards for the reference group. |
| Peer reviewer #4 | General | Overall this is a very well written, high quality, thorough, systematic review. It is informative and useful to guide clinical care. Additionally, it has identified gaps for future research. The report is a little repetitive, some references are absent and there are a number of punctuation and grammatical errors throughout the document. | Thank you for your comment; we have edited the report. |





| Commentator & Affiliation | Section | Comment | Response |
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| Peer reviewer #4 | General | There are some minor gramatical errors throughout. For example, page 22, line 32: no space between n and 5. | We have corrected this typo and reviewed the report for other errors. |
| Peer reviewer #4 | Introduction | Well structured and provides justification for the review. The questions are stated clearly and are appropriate. | Thank you for your comments. |
| Peer reviewer #4 | Introduction | Page 3, line 16-17: Indeed, chronic pulmonary disease related to aspiration is the leading cause of death among patients with severe CP. This sentence is stated a number of times throughout the document and no reference is provided. | We have added rederences for this statement. |
| Peer reviewer #4 | Introduction | page 4, line 41 - 42: Potential harms This is an incomplete sentence. | We have corrected the sentence. |
| Peer reviewer #4 | Methods | The inclusion and exclusion criteria are justified. The % of individuals required to have CP in the study population should be included in table 2. | Thank you for your comments. We have added the percent in table 2. |
| | | The search strategy is explained and details are included in the appendix to allow replication | |
| Peer reviewer #4 | Results | Question 3a aims to investigate the comparative effectiveness of tube feeding when compared with oral feeding or with nutritional and behavioural interventions. However, only pre post data are included in the summary. Data relating to the comparison groups would be useful additions to the tables. | Most studies included in the review were case series and included only pre-post data. Table 8 describes the groups represented in the studies in the first column. Given that most individual studies were noncomparative, we have provided what data are available. |
| Peer reviewer #4 | Results | I am surprised the following study was excluded from the review as not addressing the intervention of interest: Arrowsmith et al. The effect of gastrostomy tube feeding on body protein and bone mineralization in children with quadriplegic cerebral palsy DMCN 2010 This study evaluated the effectiveness of gastrostomy tube feeding on nutritional status parameters in malnourished children with cerebral palsy. | We re-examined the study and have added dat a on our outcomes of interest as reported in this study. |
| Peer reviewer #4 | Results | Anthropometric data are referred to as "scores" throughout where they should be referred to as Z-scores. | We have modified the report throughout. |
| Peer reviewer #4 | Results | It would be useful to include in table 9 the number of children who experienced GER at baseline. Did they all have GER? | We have added the information, where reported, to the table. |
| Peer reviewer #4 | Discussion/conclusion | Some research gaps are discussed and the need for good RCT's is highlighted. | Thank you for your comments. |





| Commentator & Affiliation | Section | Comment | Response |
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| Peer reviewer #4 | Discussion/conclusion | The ethical implications of conducting comparative studies of surgical interventions is discussed; however, the ethical implications of comparative studies into other nutritional interventions (eg positioning, texture modification, food thickeners, supplementation with formulas etc) are not mentioned. | We have noted that these types of studies similarly pose challenges in the Limitations section. |
| Peer reviewer #4 | Discussion/conclusion | There is no mention of future research directions for Key Question 2a an area where there is a complete absence of evidence. This is clearly an area where future research is warranted and is ethically challenging. | We have added a sentence to this effect. |
| Peer reviewer #4 | Discussion/ conclusion | page 48: The first sentence of the conclusions paragraph is incomplete. | We have revised this sentence. |
| Peer reviewer #4 | Clarity and usability | As mentioned above, the report is a little repetitive. However, the main points are clearly presented and conclusions are useful to guide clinical practice. | Thank you for your comments. |
| Peer reviewer #4 | Clarity and usability | The section relating to future research should be expanded. | We have expanded this section somewhat, as we felt able to do given that the primary need is for all comparative research in this area. We note that future research needs are addressed broadly throughout the Discussion section of the report as well as explicitly in the Future Research portion. |
| Peer reviewer #6 | General | I found the report to be meaningful for clinicians. Both the target population and audience were explicitly defined. The key questions were stated explicitly and appropriately. | Thank you for your comments. |
| Peer reviewer #6 | Introduction | The comparative effectiveness review of interventions for feeding and nutrition in cerebral palsy is presented in a format that will be useful to clinicians and policy makers. | Thank you for your comments. |
| Peer reviewer #6 | Methods | The inclusionary and exclusionary criteria were justified. The stated search strategies were logical. The definitions for the outcome measures were appropriate. The statistical methods utilized were appropriate. | Thank you for your comments. |
| Peer reviewer #6 | Results | The amount of detail presented in the results section was appropriate. The characteristics of the studies were clearly described. The key messages were explicit and applicable. The figures, tables and appendices were adequate and descriptive. The investigators didn't overlook any studies that should have been included. | Thank you for your comments. |
| Peer reviewer #6 | Discussion/ Conclusion | The implications of the findings for the behavioral and surgical interventions were clearly stated. The future research section was clear. | Thank you for your comments. |





| Commentator & Affiliation | Section | Comment | Response |
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| Peer reviewer #6 | Clarity and usability | The report was well structured and organized. The main points were clearly presented. The conclusions for surgical procedures can be used to inform policy and/or practice decisions. | Thank you for your comments. |
| TEP Member #3 | General | It was a pleasure to review this carefully prepared document on such an important clinical topic. The report does what it sets out to do: be clinical meaningful, address the key questions, which are both appropriate and well-stated and clearly define the target population and audience. | Thank you for your comments. |
| TEP Member #3 | Executive Summary | Introduction: Executive Summary: Clear, comprehensive. Minor suggestions as follows: ES-3 line 8: "suffer with" should be changed to "are affected by" ES-3: line 46/7: "may be necessary" - should this read: are often deemed necessary? ES-17 line 28: the authors state that "dumping syndrome" is related to GT - I thought dumping was primarily a problem post fundoplication not just GT placement. ES-21: Glossary: line 24- 26 Fundoplication/Nissen Fundoplication: first sentence might be clearer if it read: Surgical procedure performed for the management of GERD. ES-21 Glossary line29-30: providing for less invasiveness A clearer statement might read:to look at the abdomen and pelvis, which is less invasive and promotes faster recovery, but requires more technical skill. | Thank you for your careful reading. We have made all the changes suggested. |
| TEP Member #3 | Executive Summary | ES-21 Glossary line 31- 36: explanation is provided as to what the esophagus is, but not what the LES is. I wonder if the word esophagus needs to be explained, then the entire document especially the glossary will need to be assessed for reading level. ES-21 Glossary line 31- 36: Perhaps the statement describing aspiration should be included in the section on GERD and not GER. ES-21 Glossary line 44: Define jejunum?, clarify that J stands for jejunum | The glossary defines LES and esophagus. We have added a definition for jejunum and adjusted the definitions for GER and GERD as suggested. |





| Commentator & Affiliation | Section | Comment | Response |
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| TEP Member #3 | Introduction | Introduction: well written, concise yet thorough. Minor suggestions as follows: Page 1 line 46-7: please change "suffer with" to are affected by" Page 3 line 17: leading cause of death - should that be referenced? Page 4: "Gastrostomy has been associated with should read Gastrostomy feeding (one can have a gastrostoma without using it for feeding) Page 6: line 26: "who provide care for CP."who provide care for individuals with CP" is better. | We have made these suggested edits and added references for statements about cause of death. |
| TEP Member #3 | Methods | Methods: Yes to all qestions above. small grammatical suggestion: Page 7 line 10 - suggest remove the second "and" in the sentence | We have corrected this statement as noted. |
| TEP Member #3 | Results | Results: Detail: appropriate Characteristics clearly described: yes Key messages explicit and applicable: yes Figure, tables and appendices adequate, descriptive, applicable? yes, for the most part easy to read. | Thank you for your comments. |
| TEP Member #3 | Results | Some of the tables get a bit bogged down with a lot of information, but I don't have any solution. Information captured in the tables is important and relevant | We agree that finding the appropriate balance in the level of detail in tables is challenging. We have tried to present enough detail to help readers understand key study characteristics and outcomes while keeping the tables easy to read and understand. |
| TEP Member #3 | Results | Were any studies overlooked or "wrongly included?" I did not think of this study during the TEP process - it is very small.Relates breath swallow pattern and viscosity of liquid in children with CP with typically developing controls. Dysphagia. 2005 Spring;20(2):108-12. The effect of viscosity on the breath-swallow pattern of young people with cerebral palsy. | We excluded this study as an observation of the association of food consistency on swallowing, rather than an assessment of an intervention, which is the focus of this review. It certainly may provide important information for families, but does not meet our criteria fo this particular analysis. |
| TEP Member #3 | Results | Page 22 line 31 - space required between the word in and the number 5. | Corrected |
| TEP Member #3 | Results | Page 28 line 10. First sentence of the paragraph is not clear. ?? children who were orally or gastrostomy-tube fed | We have clarified this sentence to note that the studyincluded one group of orally fed and one group of gastrostomy-fed children. |
| TEP Member #3 | Results | Page 30 - line 7 - I don't thing the reference (83) matches the described study- It sound like one of the Mahant references (82?) This may mean subsequent references referred to on the previous page are not correct. | We have corrected the error in the references. |





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| TEP Member #3 | Results | Page 30: Table 8 - the again related to a reference - the mahant study is listed as # 83 and it is number 82 confirming a need to check references as mentioned in previous note Page 30 Table 8 - Please double check the Mahant study. It is listed as a US stdy - I think it is a Canadian paper | We have corrected the error in the references and noted that the Mahant study was set in Canada. |
| TEP Member #3 | Results | Table 8: Rempel reference is listed as 84 in the table and 83 in the reference section, similarly Shapiro is 85 in the table and 84 in the reference section. (also page 33, 34, 37, 40) Page 35 Line 39 ff. | We have corrected the error in the references. |
| TEP Member #3 | Results | The description of the Nissen fundoplication is not quite accurate. The "esophagus is closed off" is not an approprite description of the procedure. Creation of a one way valve might be better, otherwise it sounds as though the esophagus is occluded. | We have edited this description as suggested. |
| TEP Member #3 | Discussion | Discussion/ Conclusion: Implications clearly stated? yes Limitation adequately discussed? yes Omission of literature? no Future directions clearly stated and easily translated?yes | Thank you for your comments. |
| TEP Member #3 | Discussion | Page 46 - Decision-making instead of decisionmaking? | The AHRQ standard is decisionmaking. |
| TEP Member #3 | Discussion | Page 46 line 10 - please change suffer from to affected by Page 47 line 7 : spacing error before semicolon. | We have change "suffers" as noted and removed the extra space. |
| TEP Member #3 | Clarity/Usability | Clarity and Usability: Well structured and organized? yes Main points clear? yes Can conclusions inform policy and practice? yes | Thank you for your comments. |
| TEP Member #3 | General | This is an excellent report. Clear, concise, useful for clinical practice to inform the design of intervention strategies and policy decisions. | Thank you for your comments. |
| Peer reviewer#7 | General | The report is clearly written. The target population and audience are identified. Questions are clearly stated and relevant to clinical practice. | Thank you for your comments. |
| Peer reviewer#7 | General | Recommendation: The term allied health professionals is outdated. I noted use in ES page 6. When referring to intended users please indicate nurses, occupational therapists, physical therapists, speech and language pathologists, and other health professionals. | We have changed the term as noted. |
| Peer reviewer#7 | Executive Summary | The executive summary is 17 pages. I appreciate the importance of summarizing the methods. My recommendation is to indicate the systematic review process but in less detail. | We have attempted to balance the need for a concise overview with the need to include information critical for understanding the report in the Executive Summary, which is likely to be read more widely than the full report. |





| Commentator & Affiliation | Section | Comment | Response |
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| Peer reviewer#7 | General | Consider adding a 1-2 page summary written for families. | The AHRQ's Eisenberg Center develops translation materials for many AHRQ reviews and may do so for this report. In other cases, professional organizations use EPC reports to develop their own materials. It is beyond the scope of the review team to do so, but we agree that materials for families would be helpful. |
| Peer reviewer#7 | Introduction | The introduction effectively summarizes the issues for feeding in children with cerebral palsy with limited oralmotor control. The considerations for behavioral and surgical interventions and desired outcomes | Thank you for your comments. |
| Peer reviewer#7 | Methods | The methods clear, transparent, and of high quality. Supporting information is included (i.e. databases searched, search terms, criteria for including a study in the review, criteria for determining methodological quality). | Thank you for your comments. |
| Peer reviewer#7 | Executive summary | Glossary is useful. | Thank you for your comments. |
| Peer reviewer#7 | Executive summary | Outcomes clearly stated. | Thank you for your comments. |
| Peer reviewer#7 | Methods | The distinction is not made between a single subject research design and a single case report. The study by Ganz (1987) used a single subject design with no replication (n=1). Were single subject designs (multiple data points during baseline and intervention) included? | We have clarified that studies with only one participant— regardless of the number of data points—were excluded in the current review. A review by Snider and colleagues, summarized in the current review, did include studies with only one participant. |
| Peer reviewer#7 | Results | Results are clearly interpreted in the text. The Tables effectively summarize research studies. In the full report, the amount of detail provided is good. | Thank you for your comments. |
| Peer reviewer#7 | Discussion | The need for larger RCTs is appreciated. I encourage a paragraph acknowledging the challenges of experimental studies especially with a population that is medically fragile. The RCT in theory controls for factors that might contribute to change but are not known to the researcher. Some of these factors, however, might mediate or moderate the effect. The a RCT might not be the optimal design for all research. | We have noted in the Discussinsection that while RCTs are best for establishing causal inference, it is likely that they may not be optimal study designs for all questions that are important in this field of study. In particular, eliminating the confounding effect of potential mediators and moderators could result in not fully understanding the complexity in the natural history and appropriate treatment of feeding challenges. A range of study designs will be necessary to address the breadth of important questions currently unanswered. |





| Commentator | Section | Comment | Response |
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| & Affiliation Peer reviewer#7 | Discussion | Page 47 "Foundational research is needed to establish the most appropriate, patient-centered outcomes that are important to families of individuals with CP." I recommend that a sentence or two be added to the discussion in indicating that qualitative and mixed methods approaches may be effective in understand the lived experiences, preferences, strengths and needs of families. The research appraised is primarily from the perspective of the professional. | We have noted the utility of such approaches in the Discussion section. |
| Peer reviewer#7 | Discussion | I recommend adding a section - Implications for Clinical Decision Making in both the executive summary and the full report. These following sentences are embedded in a paragraph and do not appear in the executive summary. Page 77 "Understandably, treatment decisions must be made, even with inadequate evidence. Ideally, this review will help policy makers and researchers understand what types of studies are essential to lead to more informed clinical decision making." The first sentence acknowledges that decisions must be made with insufficient and/or inconclusive evidence. However, rather than elaborate on how the review might be used by health care providers and families, reference is made to the need for research. Haynes et al (2001) present a model for evidence based decision making. In addition to research, patient/client preferences, the context for intervention, and practice knowledge inform decisions. I think uptake and translation to clinical decision making would be enhanced if implications are addressed. | We have added this section to the Executive Summary as well. |
| Peer reviewer#7 | General | In our research we often ask parents to provide input when considering the implications. Have you considered obtaining input from a few families of children with feeding problems? | We cannot go back at this point and invite further comment, although the report was available for public review and comment. |
| Peer reviewer#7 | Clarity/Usability | Clarity and Usability: See discussion and conclusion on recommendations for improving usability by health care providers and families. | See response above. |





| Commentator & Affiliation | Section | Comment | Response |
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| Public reviwer (Abbott Laboratories) | General | As a manufacturer of specialized nutrition products, Abbott commends AHRQ for leading this effort to develop an evidence-based approach to improve the clinical decision making and quality of nutrition care for cerebral palsy patients. Abbott appreciates the opportunity to provide comments and recommendations on the report regarding feeding and nutrition in cerebral palsy. | Thank you for your comments. |
| Public reviwer (Abbott Laboratories) | Executive Summary | Page ES-3: We agree with the statement that individuals with cerebral palsy face many nutritional challenges and "frequently have feeding and swallowing problems that may lead to poor nutritional status, growth failure, chronic aspiration, esophagitis, and respiratory infections." Unfortunately, malnutrition in patients with cerebral palsy, such as that documented in hospital patients with the condition [1], remains high. | Thank you for your comments. |
| Public reviwer (Abbott Laboratories) | Introduction | We also agree with the comment that "caregiver burden is a significant concern as the feeding process may require considerable time and may be associated with stress and caregiver fatigue; stress and fatigue may in turn affect the feeding process." Indeed, in a study of a broader group of caregivers of children with home enteral nutrition, psychological distress and anxiety were positively correlated with caregivers' feeling of burden [2]. | Thank you for your comments. |
| Public reviwer (Abbott Laboratories) | Introduction | We agree that "no uniform decision pathway for deciding when a child should move from oral feeding to enteral tube feedings exists, but there is general consensus." However there may be need for the development of more formal decision pathways, as at least one study has concluded "children with severe CP may get their gastrostomy tube inserted too late." [3] | Thank you for your comments. It is beyond the scope of the EPC program to develop guidelines or decision pathways, but we hope that our review can provide support to organizations that do this work. |
| Public reviwer (Abbott Laboratories) | Executive Summary | PageES-4: We agree that the goal for management of cerebral palsy is "to improve the quality of life for both the child and family, through interventions that maximize independence in activities of daily living, mobility, and nutrition" but that there is limited data on potential feeding interventions and the impact of such interventions on health outcomes. Certainly this evidence-based review undertaken by AHRQ brings attention to the need for more specific research in this area | Thank you for your comments. We hope that the review will spur additional research in this area. |





| Commentator & Affiliation | Section | Comment | Response |
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| Public reviwer (Abbott Laboratories) | Executive Summary | Page ES-16-17: We also agree that: "The study of feeding and nutritional interventions for individuals with cerebral palsy is a nascent field but one that is growing" "Rigorous, comparative studies of behavioral interventions need to be conducted" "Current research is available to provide potential directions for study" "Data are absent on role of feeding interventions for adults with CP" "Prospective, comparative studies should be carefully conducted to determine what type of nutrition is appropriate for obtaining positive health outcomes without inducing excessive weight gain." | Thank you for your comments. |
| Public reviwer (Abbott Laboratories) | Introduction | Patients with cerebral palsy have poor nutritional status due to both feeding and swallowing difficulties. And as at least one study on life expectancy of children with cerebral palsy has documented, feeding skills are one of the most powerful prognostic factors for survival [4]. | Thank you for your comments. |
| Public reviwer (Abbott Laboratories) | General | Page ES-11 and Results Section Page 27 (Key Question 2a related to the Effectiveness and Modifiers of Nutritional Interventions) It is disappointing that no studies met the AHRQ criteria to address this question, although pureed food was used in conjunction with positioning and sensorimotor interventions described in the review by Snider and colleagues. | We agree and have noted the need for further research in this area in the Future Research section of the report. We note that key findings of the Snider review are summarized in the current report. |
| Public reviwer (Abbott Laboratories) | General | While no studies were identified in this review that investigated nutritional interventions, oral supplementation has been successful in improving the nutrition status of some other populations with similar eating difficulties such as the elderly [5], patients who have suffered a stroke [6], and those with neural detriments [7]. In addition to improving nutrition status, oral supplementation minimizes the risk of infection often associated with tube placement. Therefore, oral supplementation represents a valuable feeding intervention in this population, although additional research on this topic is warranted. | We have noted the need for further research on nutritional interventions in the report's Future Research section. We have also noted the potential to explore promising interventions used in other populatins for their applicability to individuals with CP. |





| Commentator & Affiliation | Section | Comment | Response |
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| Public reviewer (Aaron Krupp) | General | No specific comments. | No response needed. |
| TEP Member#4 | General | General Comments: Impressive scholarly review. Comprehensive. | Thank you for your comments. |
| TEP Member#4 | Introduction | Introduction: Proposed definition and classification of cerebral palsy, April 2005. Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, Jacobsson B, Damiano D; Executive Committee for the Definition of Cerebral Palsy. Dev Med Child Neurol. 2005 Aug;47(8):571-6 WOuld you consider use of this definition as it emphasizes the multiple systems invovled in CP not just motor and as well as function - which addresses feeding. Used +++ at AACPDM | Thank you for pointing out this reference. We have added the definition to the report's introduction. |
| TEP Member#4 | Methods | Methods: Well articulated and appropriate methods. | Thank you for your comments. |
| TEP Member#4 | Results | Results: Results well stated and described | Thank you for your comments. |
| TEP Member#4 | Discussion | Discussion/ Conclusion: Implications for future research are clearly necessary and suggestions are clearly made. | Thank you for your comments. We hope that the report draws attention to the need for further research in this area. |
| TEP Member#4 | Clarity and usability | Clarity and Usability: The conclusions be used to inform policy and/or practice decisions. The report well structured and organized. | Thank you for your comments. We hope that the report draws attention to the need for further research in this area. |